



STATE OF WASHINGTON
WASHINGTON STATE BOARD OF HEALTH
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Draft Summary of Planned Work

Genetics Task Force

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Overview

The state biennial operating budget for the 2001-2003 biennium requires the Board to convene a "...broad based task force to review the available information on the potential risks and benefits to public and personal health and safety, and to individual privacy, of emerging technologies involving DNA. The task force must consider information provided to it on

- a) incidence of discriminatory actions based upon genetic information
- b) strategies to safeguard civil rights and privacy related to genetic information
- c) remedies to compensate individuals for inappropriate use of the genetic information, and
- d) incentives for further research and development on the use of DNA to promote public health, safety and welfare.

We must report our findings and any recommendations to appropriate legislative committees by October 2002.

By October 15, the Board will name a broad based task force, reflective of the primary genetics issues it must consider under the terms of the proviso. The task force will include representation from:

- (1) local public health;
- (2) state public health;
- (3) public purchasers of medical care;
- (4) private purchasers of medical care;
- (5) health insurance carriers;
- (6) primary care physicians;
- (7) pathologists or laboratory medicine;
- (8) genetics counselors;
- (9) hospitals;
- (10) genetics ethicists;
- (11) institutional review boards;
- (12) research geneticists;
- (13) trial attorneys;
- (14) medical research institutions;
- (15) civil rights advocates;
- (16) privacy advocates;
- (17) citizens who have undergone genetic testing;
- (18) parents whose children have been helped by genetic testing;
- (19) the biotechnology industry; and
- (20) an expert in privacy laws and rules, especially as required under HIPAA.

Other interested parties, including legislators, state agency and interested citizens or private sector representatives wishing to attend meetings or be kept informed of the Task Force's work will be encouraged to do so through the Board's web page or by attending meetings.

The scope of the Task Force's considerations will be limited to the objectives set forth in the legislative proviso centering on privacy of genetic information as collected, stored and shared within the public health and medical care systems, including insurance, and the sharing of this information with employers or potential employers and life insurance underwriters as balanced against the risk of harm to scientific development and research of benefit to public health, safety and welfare. It is suggested that the Task Force's exploration of "incentives for research and development" exclude stem cell research and cloning, and focus on potentials to advance knowledge and improve practice in the context of privacy and discrimination concerns and potential regulations.

The suggested schedule for the Task Force is four to six one day meetings to be held in the SeaTac area (perhaps the Department of Health's Kent facility). To complete the work in time to meet the legislatively imposed schedule, it is suggested that the meetings occur in the following months, as follows:

| Task | Timeline |
|--|-----------------|
| The Board Solicits nominations for Task Force Membership | September 2001 |
| The Board Appoints Task Force Members | October 2001 |
| Conduct Initial Task Force Meeting to hear from Prime Legislative Actors Pro and Con; Review the Findings of the Recent Joint Select Committee on DNA Identification; Obtain Background on the Charge to the Task Force and Related Processes; and Become Familiar with Current Law and Official Policy in Washington on Regulating Genetics Privacy and Discrimination, Including Relevant Research Regulations | November 2001 |
| Conduct Task Force Meeting to Receive Evidence of Violations of Genetics Privacy Principles and/or Genetics Based Discrimination; Review and Discuss Genetics Privacy and Discrimination Problems and Policies from Other States; Discuss Options to Address Any Problems | February 2002 |
| Conduct Task Force Meeting to Review Information on Bio-tech Industry Research and Development Plans and on Desirable Incentives to Stimulate Genetics Research and Development; Receive Public Comment on Options to Address Any Privacy or Discrimination Problems Identified; Discuss and Attempt to Settle Upon Options and Possible Recommendations on Privacy and Discrimination | April 2002 |
| Conduct Task Force Meeting to Review Draft Task Force Report; Conduct Further Task Force Discussion of Possible Recommendations if Needed; and Approve Report, if Possible | June 2002 |
| Conduct Task Force Meeting to Approve Final Task Force Report and any Recommendations | September 2002 |
| Presentation of Final Report to the State Board of Health and to the Legislature (at the October Board meeting) | October 2002 |

